

# Exploring Pathways to Hospital Care for Patients with Alzheimer's Disease and Related Dementias in Rural South Western Uganda

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## Research article

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# Abstract

**Background:** In order to analyze use of health services and identify sources of delays in accessing the right care for patients with Alzheimer's disease and related dementias (AD/ADRD), understanding of care seeking pathways is needed. The objectives of this study were: (i) to explore pathways to hospital care for patients with AD/ADRD and (ii) to describe challenges experienced by the patients and their families while seeking health care. **Methods:** Using purposive sampling, 30-in-depth, semi-structured interviews were conducted among caregivers of elderly patients diagnosed with dementia from rural Southwestern, Uganda. Data was analyzed using ATLAS.Ti software. **Results:** There was variability in pathways to care from individual to individual. The points of care varied from one to four including; hospitals, clinics, places of worship and traditional healers with one to six point of care visits. Two broad themes were identified: (1) points of care choice and perceived care outcomes; (2) challenges encountered at various points of care. Most of the respondents reported use of hospitals at first and second visit to the health care point (53.3% and 67.9% respectively), but reduced to none at 5th and 6th encounters. Places of worship, clinics and traditional healer's shrine received few patients but places of worship became more common from third point of care encounter to the sixth. Major improvements (58.1%) were observed on hospital use but little or no help with prayers, clinics and traditional healers. The challenges experienced with formal points of care focused on cost of prescribed drugs, weakening effect of the drugs, health workers' rudeness, lack of skills to manage the condition, and lack of improvement in quality of life. **Conclusions:** Study findings indicate that caregivers and or families of patients with dementia go to different places both formal and informal care settings while seeking health care. However, hospital point of care was more frequent at first and second points of care visit while places of worship took the lead at subsequent visits. Although no specific pathway reported, most of them begin with hospital (formal) and end with non-formal. We recommend that health systems carry out public awareness on dementia.

## Introduction

Alzheimer's disease (AD) is the most common form of dementia in the elderly accounting for 60–80% of all cases of dementia (Islam et al., 2019). It has been reported that AD affects 2% of the population in industrialized countries (Sun et al., 2012), more than 10% of the population over the age of 65, and 50% of the population over the age of 85 (Zhang et al., 2011). Currently dementia is estimated at 47 million people worldwide, with nearly 9.9 million new cases reported each year (WHO, 2017) with 60% of the new cases coming from low- and middle-income countries (LMICs) (Olayinka & Mbuyi, 2014). The disease burden doubles every two decades worldwide but doubles in every 7.2 years in sub-Saharan Africa (Prince et al., 2015). In Uganda, data concerning the burden of AD and other dementias is scanty but one study reported that 5.5% of all elderly patients aged 60 years and above admitted to non-psychiatric wards had dementia (Nakasujja et al., 2007).

Available evidence indicates that people with Alzheimer's disease and or related dementias (AD/RD) seek health care in different ways and meet different challenges along the way (Khachaturian, 2008). The pathways and challenges vary from individual to individual. According to Carrillo et al. (2011) in the

healthcare access barriers mode, they categorize factors along the pathways to care to include financial, structural and cognitive. The financial barriers like lack of insurance or money to meet treatment bills limit access to medical treatment, structural barriers like multi-step care processes or multiple locations for tests and specialists reduce accessibility to care, while cognitive barriers like limited knowledge or awareness about the disease and availability of health facilities cause poor health outcomes (DeVoe et al., 2007).

Studying the pathways to care is critical to describing health services utilization, characterizing of the sources of delay in attending the right care, and identifying the possible remedies. Prior research shows that these care pathways are not usually random but they are structured by a combination of psychosocial and cultural factors (Lahariya et al., 2010). The study by Nakasujja et al., (2007) at Mulago national referral hospital in Uganda covered patients who had visited the hospital but did not take into account where these patients passed to reach the hospital and what could affect their path to the facility. Yet, varied beliefs on dementia among family members may cause them seek care in different ways (Hindley et al., 2016). Our study explored pathways to hospital care and the challenges experienced by patients and their families in rural southwestern Uganda.

## **Methods, Aim And Design Of The Study**

This study aimed to explore the pathways to hospital care for patients with Alzheimer's disease and related dementias and the challenges they meet in the process. It was a descriptive cross-sectional study conducted among caregivers of patients with Alzheimer's disease and related dementias using in-depth interviews in rural southwestern Uganda.

### *Study setting*

The study participants were selected from specific homes and psychiatric wards of three referral hospitals of: Mbarara Regional Referral Hospital (MRRH), Kampala International University Teaching Hospital (KIU-TH) and Kabale Regional Referral Hospital (KRRH). The three health facilities are geographically distributed to represent the southwestern region of the country and receive patients from lower health facilities in the region.

### *Participants' recruitment and Sampling*

The participants were caregivers who had been taking care of elderly patients (60 years and above) diagnosed with dementia. The study included caregivers who had stayed with the patients for at-least 6 months and above, aged 18 years and above. Most of the caregivers who were the respondents in the study were females (19 females and 11 males), and were majorly primary caregivers (table 1). The mean age for the respondents was 46 years with youngest at 22 and the oldest at 70. Details of the demographic characteristics are indicated in Table 1. Caregivers who were unable to give adequate information due to various reasons like serious sickness or drunkenness were excluded from the study.

Purposive sampling was used to recruit participants from medical records in the psychiatry departments of the three hospitals by medical personnel to get contacts of caregivers of patients who had attended in the last one year and those attending at the time. Those attending at the time were interviewed from the facility while those from past records were contacted by telephone calls and followed up to their homes where they were interviewed from. A total of 30 respondents participated in this study.

### Procedure

In-depth interviews were conducted by the lead author (NK) and two trained research assistants between December, 2018 and January, 2019. Each interview lasted approximately 40 minutes and was audio recorded. The interviews were conducted in either Runyankore (native language of the area) or English depending on convenience of the respondent, and backed by field notes.

### Data collection and study tools

A semi-structured interview guide was developed by NK in consultation with GZR, BG and ESO. Questions were based on the objectives of the study. The interview guide (Additional file 1) was translated to Runyankore-Rukiga (native language of the area) by a native person of the area and back translated to English by one research assistant to ensure consistence. Audio recorders were used to enhance data capture and retrieval to correlate the hand written information. Participants were interviewed to obtain information concerning their pathways to care and challenges met while seeking care. All responses were prompted by open ended questions.

### *Data analysis and quality control*

Data was transcribed verbatim and translated into English by the two research assistants. The transcripts were read several times by the lead author (NK) and ESO to get familiar with the data and imported in ATLAS.Ti, version 7, a qualitative data management software (Muhr, 2013). We (NK and ESO) used six samples of transcripts to develop codes in accordance with points of care visited, reasons for the choice of point of care, outcomes from each point of care and the challenges encountered at the different points of care. The two authors then used developed codes to code and reorganize the whole data into categories by comparing statements from the respondents. Repeated/common patterns and systematic relationships guided the formation of categories and themes according to the objectives of the study.

## Results

The study findings indicated that there was variability from individual to individual in the pathways to care undertaken by caregivers and or families of patients with Alzheimer's disease and related dementias. The points of care varied from one to four and included; hospitals, clinics, places of religious worship and traditional healers shrines while six encounters/visits of these health care points were observed.

There were two broader themes captured: (1) the points of care choice and perceived care outcomes; (2) challenges encountered at various points of care. Apart from one respondent, the rest had visited more than one point of care. The choice for each point of care was dependent on several factors ranging from

knowledge of the individual on the disease, financial status and religious background of the individual, the outcomes from points of care visited previously and challenges experienced while seeking care. Most of the respondents reported use of hospitals at first and second visit of seeking health care, but religious places of worship became more common with subsequent points of care visits while traditional healers received minimal.

Figure 1. Frequency and points of care visited sequentially by patients seeking care for Alzheimer's disease and related dementias in rural Southwestern Uganda.

*Key:* Colors correspond to the point of care where patients started seeking health care. The red arrows indicate the pathway from hospital point of care. The black arrows indicate the pathway from clinics; the blue arrows indicate the pathway from the traditional healers' shrines and the green arrows indicate the pathway from places of worship. Visit refers to health seeking care encounter. Numbers (percentage) in boxes indicate respondents who visited that particular point of care for that encounter/visit. Note that total number of patients/caregivers from one visit to another go on reducing as some used few health care encounters than others.

## Points of care choice and perceived care outcomes

### Hospital point of care

Of the four points of care visited, the most frequently visited point of care at initial visit was hospitals (53.3%) followed by clinics (36.7%), traditional healers (6.7%) and places of religious worship (3.3%). For hospital use, most of the respondents reported use of the facility at first and second health seeking encounter (53.3 and 67.9% respectively) but reduced to 19.2% and 22.2% for 3<sup>rd</sup> and 4<sup>th</sup> point of care visit but none at 5<sup>th</sup> and 6<sup>th</sup> visit (Figure 1).

Several factors were said to have influenced selection of points of care. For example, the majority of respondents who chose hospital as their first point of care did so because their patients had some other illnesses as indicated in a quote below;

*"That one (forgetfulness) cannot be treated, its old age, when the knowledge reduces can you rewind it (meaning there is no treatment for memory loss). We just took him to hospital because of ulcers and pressure". (Female caregiver - wife (ID#06))*

Whereas some thought it was a result of stress and many thoughts from loss of their dear ones like children, others saw the condition new to them and strange. This prompted them to seek health care from trained personnel as shown by the quote"

*".....she got an attack which I could not manage because I had never seen that condition, so I didn't understand it. So I took a video and showed it to him (doctor) that is when he told me that this is*

*dementia. When I reached home, I googled and found that those attacks are called seizures that are symptoms of dementia". (Female caregiver—daughter (ID#05))*

For those who visited hospital at their second and third health care encounter, the major reasons were lack of improvement (inability to manage the condition) from previous points of care visits and worsening of the condition despite all the efforts done. These findings are demonstrated by the following quotes:

*"The doctor in the nearby clinic couldn't manage the condition and the condition was worsening, and the doctor there told us to go to the National Mental health referral hospital. We went there and admitted her for a month as I said before". (Female caregiver—daughter (ID#024))*

*"When we saw the condition worsening and he started to get lost, we decided to take him there (meaning hospital) so that they give him medicine and he may stay in one place but he did not respond and he continued moving aimlessly". (Female caregiver—wife (CG#02))*

*"We used the medicine for like two months and it did not help her, the arms even started shaking, when she failed to respond and we went to the doctor he told us that we stop the drug for two months but for me I saw that she was still in pain. When he discharged us we went to the psychiatry department". (Male caregiver—son (CG#04))*

In terms of the outcomes of the care seeking, most of the respondents (58.1%) whose first point of care was hospital acknowledged some improvements and reduced health deterioration upon visitation and condition management. However, there were few respondents who reported no improvement or negative outcomes such as increased body weakness in patients as a result of medications as illustrated by the quote below:

*"When he started on the treatment something that could make him move at night stopped .... the medicine made him so weak and became calm and from there he stabilized". (Female caregiver—daughter-in-law (CG#14))*

One other quote:

**"She is not completely stable but she is better than how she used to be, she can recognize a few people now". (Female caregiver—granddaughter (CG#01))**

The outcomes of hospital visits as the 2<sup>nd</sup> and 3<sup>rd</sup> point of care seemed to be indifferent from those of initial point of care. The respondents reported some relief and improvements on the symptoms of dementia.

Clinic point of care

Respondents who reported to have used clinic as one of their points of care did so mainly due to proximity of these health facilities and or because they went there primarily for physical symptoms of illness such as suspected malaria or other unspecified symptoms.

*“We were not sure of the problem but we thought maybe it is cerebral malaria that’s when we took her to the clinic (name of clinic withheld) and they said they cannot manage the condition .....”. (Female caregiver—daughter (CG#24))*

In terms of outcomes, clinics in general seemed to offer limited improvement to symptoms and respondents had to continue searching for appropriate health care as indicated by the quote below;

*“Ever since he got all that medication from there he has never got any help” (improvement). (Female caregiver—wife (CG#06))*

Places of religious worship point of care

This point of care received six patient encounters/visits unlike other type of care which received less, and the visits were nearly twice as much as the hospital at third point of care encounter. Although there was minimal use of places of religious worship at 1<sup>st</sup> and 2<sup>nd</sup> points of care visit, it was more preferred in subsequent visits. That is; from 1<sup>st</sup> point of care visit to the 6<sup>th</sup> in the order of 3. 3%, 10.7%, 61.5%, 44.4%, 75% and 100%.

There were varied reasons for use of places of religious worship as initial point of care. The single respondent who used place of religious worship at initial point of care linked the condition to demonic/satanic attacks and could think of knowing or chasing the demons through prayers. Same reason was given by other respondents at subsequent visits of this same point of care. Some believed in spiritual healing (of any problem) while others thought patients would speak out demonic voices upon prayers. Some quotes to demonstrate these findings are shown below;

*“When she tells you that in her dreams she saw people like the dead people calling her, then like the following day she falls sick, we could call the prayer people to come and pray for her, then after the prayers she gets better that’s when we got to know the problem (meaning demonic attacks)”. (Female caregiver—daughter (CG#26))*

**“You know when you pray to God he listens and answers your prayers so she may get healed because of the prayers. We have hopes”  
(Female caregiver—daughter (CG#26))**

**“We would pray that a miracle happens and we see her getting healed”. (Female caregiver—daughter-in-law (CG#03))**

Most of those respondents who used places of religious worship as 2<sup>nd</sup> point of care encounter and onwards, reported lack of improvement from health facilities they had visited before, and seemed to have lost hope on patient recovery from those facilities, and so resorted to religious prayers. Others however, reported similar reasons as in the initial point of care citing demonic attacks and so sought refuge in religious prayers. The findings are indicated by the quotes below;

*"The patient was not getting cured; the church people would come here and pray for us, tell us to be patient with her and keep taking care of her until God calls her". (Female caregiver—daughter-in-law (CG#07))*

*"Why we went for prayers, they (meaning other people) told us that when a person has such mental illness and is prayed for she may fall down and speak if they are demons and you can be able to know what is bothering her". (Female caregiver—daughter (CG#11))*

In terms of outcomes, respondents whose first point of care was places of religious worship did not see any improvement in the symptoms, and thought the symptoms are part of aging. Verbatim quote:

**"... that one (meaning forgetfulness) is old age that has no medicine and there is no cure for it". (Female caregiver—daughter (CG#26))**

Despite lack of improvement reported at this point of care, positive complements and hence emotional support have been attached to places of religious worship as one respondent reported below;

**"There was no improvement, they would come to comfort us to be patient, and on how we can take care of her and not regretting". (Female caregiver—daughter-in-law (CG#07))**

On the other hand some respondents reported use of both places of religious worship and hospital in tandem, and so were not sure of what caused observed improvement in the symptoms of the condition.

## **Traditional healer's shrine point of care**

This point of care was visited from 1<sup>st</sup> to 5<sup>th</sup> health seeking care encounter but not in 6<sup>th</sup> one. Most of the respondents whose first point of care was traditional healers' shrine had never seen such kind of condition and did so because they believed their patients had family issues (meaning demonic attacks) and would be healed by these people. Those who visited this point of care in subsequent point of care encounters mentioned similar compelling factor of being confused with the disease and thought it was due to family problems. The quotes below demonstrate the findings;



*“...we first went to traditional healers because we had not known the disease; this disease in its initial stages its confusing, for us we thought that they were traditional things...”. (Female caregiver—wife (CG#10))*

*“Staying with someone and he or she starts doing uncoordinated/wrong things and people in the village convince you that it is about family problems which need traditional healers”. (Female caregiver—daughter (CG#11))*

Some of the respondents who did not meet their expectations of cure from initial types of care like health facilities looked for alternative means of helping their patients. They were particularly going to witchcraft or herbalists for herbal medicine.

**“....because he (meaning patient) usually hears those adverts from the radios he would go and buy the herbal medicine for himself”. (Female caregiver—wife (CG#19))**

In terms of outcomes, all respondents who visited the traditional healer’s shrines were very disillusioned with the results. None of them reported any improvement. Majority believed that traditional healers were liars and had no skills to manage the symptoms as indicated below;

**“For sure I will be deceiving if I say they helped us. We didn’t get any help from witchdoctors instead he (meaning patient) almost lost his life from there”. (Female caregiver—wife (CG#10))**

## **Challenges encountered at various points of care**

### **Challenges encountered at Hospital point of care**

Respondents reported a range of challenges related to various points of care visited in efforts to seek help for symptoms of dementia. However, these challenges varied from one point of care to another. For those participants whose first point of care was hospital for example, mentioned lack of drugs as the main challenge faced. The respondents indicated that there was always stock out for the prescribed drugs and they were forced to buy them.

Like in initial point of care visit, all other visits of this point of care presented a similar financial challenge of buying prescribed drugs as shown the quote below;

*“At specialized hospital they asked money for buying medicine because they were not available in the hospital, to test blood and even for the CT scan but we did not get it, and he worsened and so we took*

*him back home. We had bought medicine for the whole week". (Female caregiver—wife (CG#02))*

Additionally, some respondents indicated that drugs from hospitals worsen the symptoms of the condition and so end up leaving them. Others reported rudeness as one of characteristics of health workers in the health facilities.

## **Challenges encountered at Clinic point of care**

According to participants' responses, health workers at the facility couldn't manage the condition and some did not understand it. Verbatim quote:

**"The doctor couldn't get and understand what was exactly disturbing her and that led to treating it as mild malaria". (Female caregiver—daughter (CG#24))**

The challenges encountered at subsequent visits of this point of care were no different from those of visiting it at first encounter, with respondents reporting poor management of the condition.

## **Challenges encountered at places of religious worship**

Whereas outcomes from this point of care were negative with positive complements, respondents generally reported no challenges experienced during health care seeking process at this point of care.

## **Challenges encountered at traditional healers' shrine point of care**

The caregivers called it wastage of money as their medicine did not help their patients all. The response from one caregiver among those who visited this point of care was not impressing at all as shown by the quote below:

*".....he wanted us to sit on skins of certain animals of which I never accepted then we sat on normal sits in the sitting room, and he told me that since I have rejected to do his things my grandmother will not get healed, he wanted us to be cut and put his herbs in our blood but we refused so it was not easy". (Female caregiver—granddaughter (CG#28))*

## **Discussion**

The study explored pathways to hospital care undertaken for patients with Alzheimer's disease and related dementias and also challenges experienced in the process of seeking care. The pathways to care varied considerably from individual to individual due to the interplay of various factors. Six visits/encounters of health care points were observed and the four points of care visited were; hospital,

clinic, traditional healers shrine and places of religious worship. Each participant would visit one to four of the care points once or more. Most of the respondents indicated use of hospital point of care at initial and second point of care visit and numbers reduced gradually. While places of religious worship, clinics and traditional healers received few patients at initial visit, places of religious worship became more common with subsequent care visits. Major improvements were observed on hospital use but little or no help with places of religious worship, clinics and traditional healers. Financial incapacitation, management incapability at particular points of care and lack of expected outcomes were the main challenges encountered.

## Points of care choice and perceived care outcomes

While hospital dominated as the first and second point of health care, it was very minimal at fourth and completely unvisited in the fifth and sixth points of care. High use of hospitals at initial (and second) points of care visit indicate strong belief people have in the formal sector particularly at hospital level as they expect health professionals/expertise at the facility (Handley et al., 2017). This is supported by the observed outcomes where participants reported some improvements in the symptoms of the dementia.

However, opting for non-formal pathways like places of religious worship and traditional healers' shrine at initial points of care visit could be a consequence of knowledge gap on the disease as 76% of the caregivers attributed the disease to normal aging process, a scenario that has been previously reported (Beard, 2004, Hindley et al., 2016). Also the rare manner in which symptoms of dementia presented to the caregivers for example bad dreams, hallucinations, irrational talks etc. which resemble demonic attacks (Uwakwe, 2000) caused them to opt for spiritual prayers or traditional healers. This is in agreement with people's strong belief in spiritual healing as reported by Charan and colleagues (2018). Also the explosion of Pentecostal churches and other prayer warriors, religious healing of late has become one of the most popular interventions for psychiatric and neurologic disorders (Uwakwe, 2000) and emotional support (Lynn et al., 2014).

Opting for non-formal pathways from hospitals at subsequent points of care seemed to be a consequence of challenges involved in the formal sector like financial constraints hence inability of some people to buy drugs at health facilities/hospitals due to stock-out of prescribed drugs, and also lack of improvement in quality of life as expected at the facility (Salgado et al., 1994). Also studies have shown that religion and hence prayers becomes increasingly important in times of illness (Rochmawati et al., 2018) and this agrees with the study findings where most respondents especially from 3<sup>rd</sup> point of care went to places of religious worship.

The observed minimal visits to clinics (and health centers) were not surprising. While proximity to these facilities led some people to visit them for treatment of other ailments, lack of trained health care professionals to handle mental health disorders at clinics/health centers might be the reason behind low visitation of this care point. This is consistent with Uganda's Ministry of Health strategic plan (MoH, 2010) where specialized clinical services for mental health disorders are only provided at regional referral

hospitals. Moreover, these regional referral hospitals receive patients from the lower health facilities such as clinics and health centers.

## Challenges encountered at various points of care

At hospital level, the major challenge experienced by most participants was lack of drugs at the facilities due to stock-out for prescribed drugs. This is common in Ugandan health systems particularly in government facilities (Lahariya et al., 2010). Whereas some could dig deeper into their pockets or sell property to meet financial needs of buying prescribed drugs outside hospitals, others could not manage and had to resort to other means of care support such as religious prayers. That could explain the increased number of religious prayer visits after formal health care encounters.

Some participants indicated that drugs from hospitals were worsening the symptoms of dementia and can be attributed to errors in medication by the patient/family members (Field et al., 2007) or from clinical settings (Forster et al., 2003). Also poor response after multiple treatment options in patients with dementia has been reported (Bhamra et al., 2018) even with adverse central effects especially when using opioid analgesic drugs (Bishara and Harwood, 2014).

At clinic level, the inability of health workers to deal with the condition is well understood and expected. Most of the clinics in rural setting are managed by nurses and clinical officers who are not well trained to handle complicated mental disorders like dementia that need specialized medical attention (WHO, 2008).

In the informal pathways to care, use of traditional healers shrines was more witnessed in rural areas than semi-urban or urban areas, a scenario that has previously been reported in Nigeria (Uwakwe et al., 2009).

Overall, existing challenges including cost of prescribed drugs, perception of lack of efficacy of the drugs, lack of compassion from health workers, limited expertise in specialized care for mental health, unexpected outcomes from the health facilities may have a greater impact on under-utilization of formal health care services for patients with AD/RD than the observed/perceived reality causing a shift from formal to informal care settings as reported by (Ransford et al., 2010). The minimal challenges experienced at places of religious worship is linked to devotion and religious belief people have in spiritual healing (Charan et al., 2018) and so influenced the formal to informal care shift in search of health care which is in line with the statement by Agbaje and Babatunde (2005) who stated that "every ailment has spiritual implications and that drugs alone are not adequate," and medicine alone is not enough for treatment of dementia and other neurological and psychiatric symptoms.

### Limitation

The study only covered those who had visited hospitals or received formal diagnosis leaving out those meandering in the informal care settings and have not reached hospital point of care.

## Conclusion

The study explored pathways to hospital care undertaken for patients with Alzheimer's disease and related dementias and also challenges experienced in the process of seeking care. The pathways to care varied considerably from individual to individual due to the interplay of various factors. Six visits/encounters of health care points were observed and the four points of care visited were; hospital, clinic, traditional healers shrine and places of religious worship. Each participant would visit one to four of the care points once or more. Most of the respondents indicated use of hospital point of care at initial and second point of care visit and numbers reduced gradually. While places of religious worship, clinics and traditional healers received few patients at initial visit, places of religious worship became more common with subsequent care visits. Major improvements were observed on hospital use but little or no help with places of religious worship, clinics and traditional healers. Financial incapacitation, management incapability at particular points of care and lack of expected outcomes were the main challenges encountered.

## Points of care choice and perceived care outcomes

While hospital dominated as the first and second point of health care, it was very minimal at fourth and completely unvisited in the fifth and sixth points of care. High use of hospitals at initial (and second) points of care visit indicate strong belief people have in the formal sector particularly at hospital level as they expect health professionals/expertise at the facility ([Handley et al., 2017](#)). This is supported by the observed outcomes where participants reported some improvements in the symptoms of the dementia.

However, opting for non-formal pathways like places of religious worship and traditional healers' shrine at initial points of care visit could be a consequence of knowledge gap on the disease as 76% of the caregivers attributed the disease to normal aging process, a scenario that has been previously reported ([Beard, 2004](#), [Hindley et al., 2016](#)). Also the rare manner in which symptoms of dementia presented to the caregivers for example bad dreams, hallucinations, irrational talks etc. which resemble demonic attacks ([Uwakwe, 2000](#)) caused them to opt for spiritual prayers or traditional healers. This is in agreement with people's strong belief in spiritual healing as reported by Charan and colleagues (2018). Also the explosion of Pentecostal churches and other prayer warriors, religious healing of late has become one of the most popular interventions for psychiatric and neurologic disorders ([Uwakwe, 2000](#)) and emotional support ([Lynn et al., 2014](#)).

Opting for non-formal pathways from hospitals at subsequent points of care seemed to be a consequence of challenges involved in the formal sector like financial constraints hence inability of some people to buy drugs at health facilities/hospitals due to stock-out of prescribed drugs, and also lack of improvement in quality of life as expected at the facility ([Salgado et al., 1994](#)). Also studies have shown that religion and hence prayers becomes increasingly important in times of illness ([Rochmawati et al.,](#)

2018) and this agrees with the study findings where most respondents especially from 3<sup>rd</sup> point of care went to places of religious worship.

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health care which is in line with the statement by [Agbaje and Babatunde \(2005\)](#) who stated that “every ailment has spiritual implications and that drugs alone are not adequate,” and medicine alone is not enough for treatment of dementia and other neurological and psychiatric symptoms.

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## Abbreviations

AD/RDs Alzheimer’s disease and Related Dementias

MADRI Mbarara Alzheimer’s Disease and Related Dementias Initiatives

MUST-REC Mbarara University of Science and Technology Research Ethics Committee

NIH National Institutes of Health

UNCST Uganda National Council for Science and Technology

LMICs Low- and middle-income countries

## Declarations

#### Acknowledgements

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#### Availability of data and materials

All datasets and materials used and/or analyzed in this current study are available from the corresponding author on reasonable request.

#### Authors’ contributions

All authors contributed to the design of the study, data analysis and writing of the manuscript. The first author (NK) wrote the first draft and the other authors (GZR, BG, EW and ESO) contributed significantly to

the revision of the draft. NK and ESO did the data analysis. CO was the senior researcher on the team for providing overall guidance right from protocol development to the final manuscript.

#### Ethics approval and consent to participate

This study was approved by the Uganda National Council for Science and Technology (UNCST) and Mbarara University School of Science and Technology (MUREC1/7). Further permissions were obtained from the hospital directors and local council authorities. Written consent was obtained from all study participants.

#### Consent for publication

Not applicable.

#### Competing interests

The authors declare that they have no competing interests.

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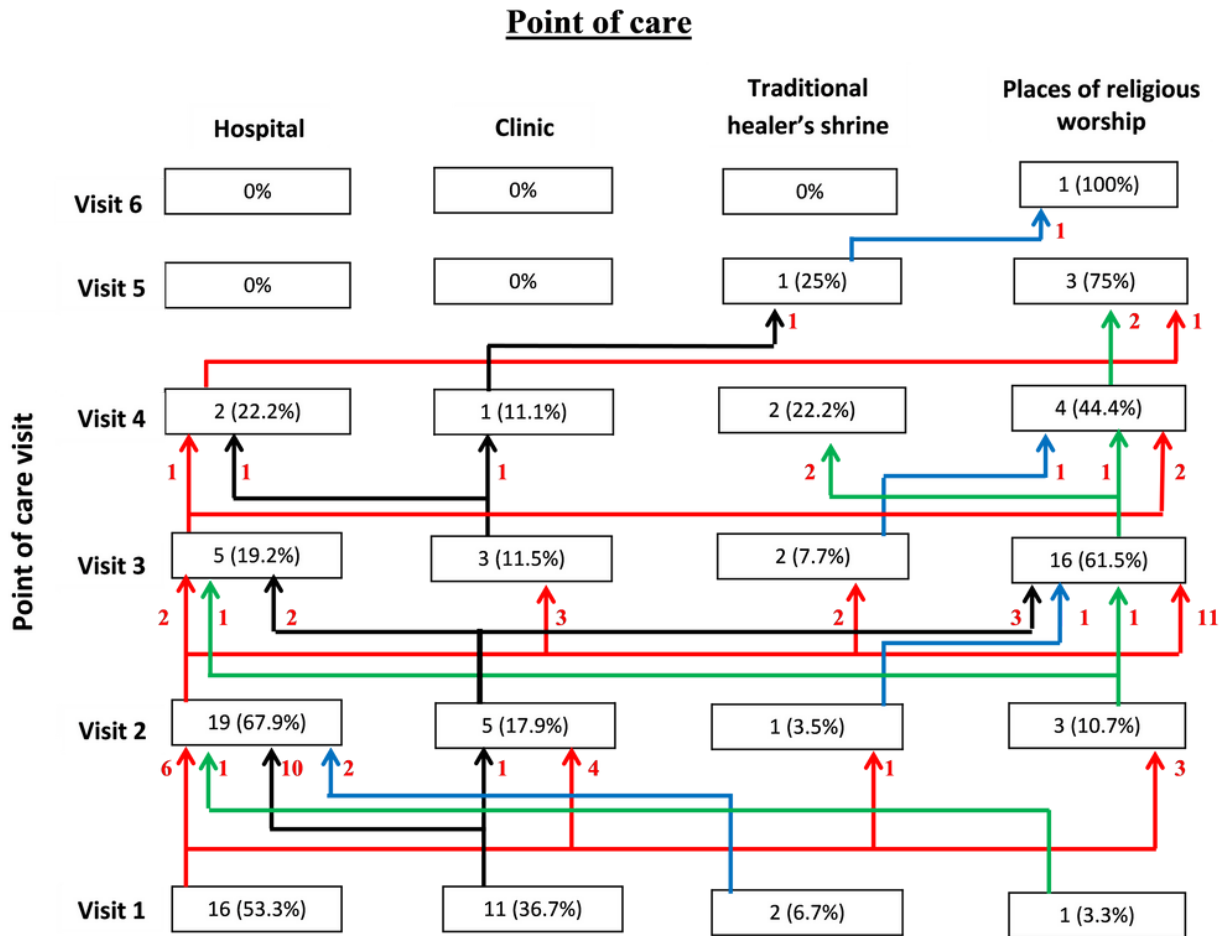
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## Table

Table 1. Demographic characteristics of participants (n=30) showing how the patients are related to them. \*\*Demographic characteristics of 3 respondents are missing.

Demographic characteristics	Mean ranges & Categories	Numbers of participants**
Gender	Females	17
	Males	10
Age (years)	18-29	6
	30-39	3
	40-49	9
	50-59	5
	≥60	4
Relationship with patient	Mother	12
	Father	3
	Mother-in-law	2
	Father-in-law	1
	Grandmother	3
	Grandfather	2
	Husband	3
	Wife	1
Level of education	Not at all	2
	P1-P7	9
	S1-S4	6
	S5-S6	2
	>S6	8

## Figures



**Figure 1**

Frequency and points of care visited sequentially by patients seeking care for Alzheimer's disease and related dementias in rural Southwestern Uganda. Key: Colors correspond to the point of care where patients started seeking health care. The red arrows indicate the pathway from hospital point of care. The black arrows indicate the pathway from clinics; the blue arrows indicate the pathway from the traditional healers' shrines and the green arrows indicate the pathway from places of worship. Visit refers to health seeking care encounter. Numbers (percentage) in boxes indicate respondents who visited that particular point of care for that encounter/visit. Note that total number of patients/caregivers from one visit to another go on reducing as some used few health care encounters than others.

## Supplementary Files

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